

SELF-ADVOCACY/LEADERSHIP TRAINING

What is self-determination and self-advocacy?

Self-determination consists of seven components:^{lxiv}

- Self-awareness - the ability to identify and understand one's needs, interests, strengths, limitations and values.
- Self-advocacy - refers to the ability to express one's needs, wants and rights in an assertive manner.
- Self-efficacy - self-confidence - the belief that one will attain a goal.
- Decision-making - complex skill of setting goals, planning actions, identifying information to make decisions, and choosing the best option to reach one's goals.
- Independent performance - the ability to start and complete tasks through self-management strategies.
- Self-evaluation - the ability to self-assess performance and determine when a goal or task has been satisfactorily completed.
- Adjustment - the process of revising one's goals and plans to improve performance or success.

The national self-advocacy organization, Self-Advocates Becoming Empowered (SABE), defines self-advocacy as the following:

[It] is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe in.

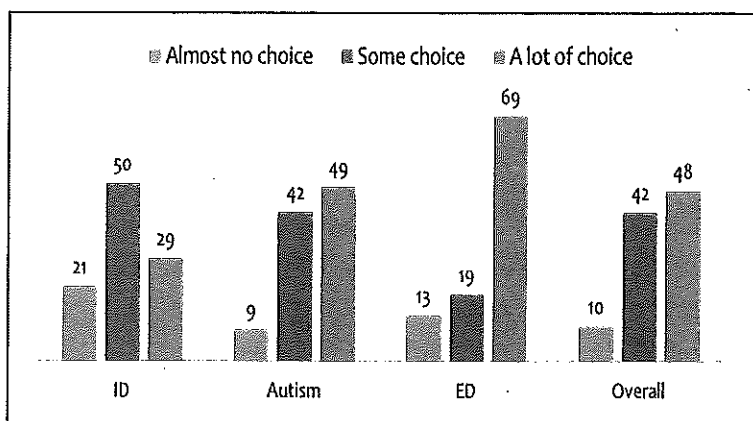
Simply put, self-determination means knowing and doing what is best for oneself, and self-advocacy means sharing this information and supporting each other collectively in fighting discrimination and other barriers.

The Status of Self-Determination and Self-Advocacy

Data from the 2015 adults with DD survey (Appendix C) and adolescents with DD indicate that few have opportunities to self-advocate and that the incidence of self-determination is low for adolescents. For instance, data from ADDPC's Graduation Cliff report indicated that learning how to self-advocate impacted adolescents' perception of outcomes. Less than half of the sample of adolescents indicated they had choice over important aspects of their educational life, such as what classes to take, what school activities they participate in, and what IEP goals they would target.

Students with more intensive support needs indicated less control and decision making in the IEP process. A large majority of adolescents indicated that adults are helping them with their decisions, but only half indicated that adults listen to them, leaving the adolescents to feel disempowered.

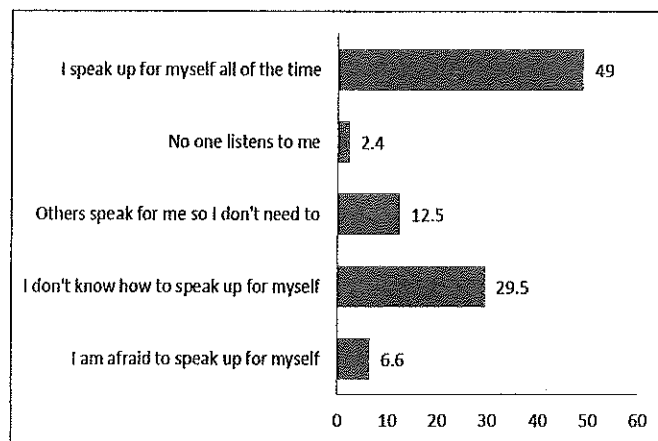
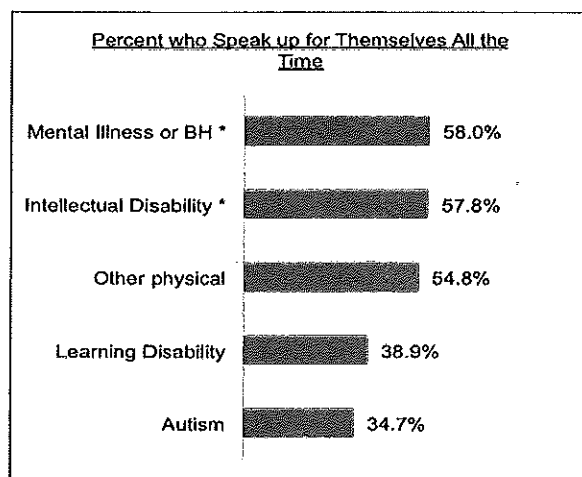
Choice over IEP



Having the opportunities to engage with peers without disabilities also was important for gaining employment. For instance, the research indicated that "Having contact with peers" (at least a little bit and frequently) was associated with being three times more likely to have paid work. Additionally, "Being involved with groups that were mostly students without disabilities" was associated with their being seven times more likely to have paid work. However, only half of the respondents indicated they were in extracurricular activities. This means the opportunities where self-advocates would engage in activities to make social connections to learn about work opportunities or practice self-advocacy were far less than needed to build those skills. And, the isolation these individuals experience is very real for some.

Being able to speak up for oneself has important implications for adult consumers in Arizona, yet Arizona falters in this area. In the 2015 survey of adults with DD (Appendix C), only 49% of respondents state that they speak up for themselves all of the time – those with autism and learning disabilities were less likely to do so. Over 40% didn't know how to speak up for themselves or were afraid to.

Percent who agree (%)



Among those who speak up for themselves, there are real implications. While they are more likely to worry about things, such as having enough money and their health, they are also active. They are more likely to work and get a paycheck, exercise, volunteer in the community, and

play sports. They are also more likely to be happy with the services they are receiving, have a bank account, and be aware of the minimum wage.

Ten self-advocacy groups across the country and in Arizona were interviewed to determine how they measured success, goal development, and barriers to self-advocacy. It was clear that self-advocacy went beyond advocating on policy issues. Members also used these groups to socialize and help each other with day to day problems. Supporting self-advocates to participate in both regional and national self-advocacy activities was a priority among the groups. Doing so helps these members realize they are part of a larger movement and motivates them into action. Repeated interactions and connections with other self-advocates at the regional and national level provide them with relationships to support advocacy work within the state and to obtain new information to share with self-advocates in Arizona.

However, they indicated that limited support for travel reduces how much Arizona will be represented at the national level. The individuals also indicated the need to create a state conference and technical assistance center to promote, train, and sustain self-determination and self-advocacy for individuals with developmental disabilities. One of the other self-advocacy organizations hosts a self-advocacy conference but can only support 89 self-advocates' attendance. With transportation always a barrier, the conference in Payson is difficult for many to participate. They also indicated the need for funding for lodging and transportation as well as involvement in research and development. Using self-advocates as part of the process for research, program development and implementation was also reiterated in teacher education.

Another barrier for these groups is recruitment and recognition by the community that self-advocacy is important. Since many members do not have access to the internet, self-advocacy group rely on organizations to help recruit, but many have stated that organizations often don't see self-advocacy as a priority. In a 2015 service providers survey, 74% of respondents had received person-centered care training, but only 47% think that individuals with disabilities are capable of representing themselves as advocates on issues critical to their quality of life (Appendix D). Of the sample, 30% are direct care workers, the rest are administrators or executives. The same lack of priority of teaching self-advocacy was noted in Arizona schools. High turnover and job hopping makes it difficult to sustain teachers and a direct care workforce to support self-advocacy and self-determination skills and activities.

In addition, communicating with members between meetings is difficult. Some rely on face to face communication or email. Rarely is social media used. As a result, many of these groups are small and flounder with small budgets, few who can take leadership roles, and a very small base of members. Some groups have used technology to mitigate the transportation barriers, but the organizer had to teach the members how to use it as part of the group's activities. All parties expressed the need to expand opportunities for self-determination and for self-advocacy train-the-trainer types of programs so that these groups are self-sustaining.

Regional summits regarding the self-advocacy movement for people with IDD were held in Spring 2011 and Spring 2012 with the goal of determining the condition of self-advocacy groups

across national, state, and local levels; and to plan for action steps to take to strengthen the advocacy movement at both the state and national level. The summits were a collaborative effort among national self-advocacy groups and their allies. State themes around self-advocacy included self-advocacy training for people and their families, including the use of peer mentoring; youth advocacy training, leadership development, and chapters; family support; speaking up for oneself regarding guardian issues; and voting training.

Major themes concerning self-advocacy included access (technology and transportation); education (improving inclusive education, disability history); employment; growing self-advocacy (leadership development, peer mentoring); inclusion (in boards and commissions; self-advocates working in DD organizations); organizational development; policy; projects; and other activities such as informing the public through radio shows and self-advocacy in governments. Data from the summit indicates that Arizona is doing some of this work, such as improving organizational development by utilizing technology and growing individual self-advocacy by conducting voter training.

Best Practices

Several states have made progress in building self-advocacy training and leadership skills of self-advocates including Minnesota, Massachusetts, and Maine. The national summits on self-advocacy identified six areas of growth in the future of self-advocacy: training and leadership development (training, mentoring, and leadership opportunities); infrastructure to support self-advocacy (local and regional, statewide, funding); cross disability coalitions, partnerships, and allies (this was reiterated with interagency coalitions); public education (public attitudes and knowledge about self-advocacy, employers), community services, and supports. Some suggestions included self-advocacy training centers as the "fourth leg of the DD act" or initiatives to collaborate to build self-advocacy. Self-advocates could serve as partners to inform state plans and policies, and self-advocate members of DD councils and other commissions at the local level can help drive state and local policy for individuals with DD.

There are several existing resources and activities available to self-advocates:

- ACDL has comprehensive guides on the rights of self-advocates on a wide range of topics, including understanding legal rights under the ADA. These guides are useful for self-advocates.
- People First of Arizona is collaborating with the Southwest Institute for Families and Children through a funded project (Administration on Intellectual and Developmental Disabilities) that aims to help individuals with IDD to advocate across Colorado, Arizona, Texas, and New Mexico. The group has two goals: (a) to have Arizonans with DD to know their rights and (b) to have Arizonans with DD to have informed voting decisions. One of the first activities the group has engaged in is a webinar titled "50 statements on legislative actions." The webinar shared 50 statements on the purpose of legislative advocacy and provided participants with instructions on how to share stories with legislators to change laws that affect individuals with developmental disabilities (e.g.,

email, phone call, in-person meetings). The group intends to provide additional support via video blogs. Expanding this program is important, and perhaps linking these opportunities and supports across disability sectors may expand the understanding of people with disabilities.

- This is My Life program is a self-advocacy training program that provides individuals with disabilities training to speak up and advocate for themselves. There are only two trainers in this program but the organization and self-advocates indicated they would like to train more individuals to train other people with DD to build self-advocacy and self-determination skills. There may be a way for ADE to partner with this group to provide technical assistance to schools for implementing self-determination and self-advocacy training and in improving employment for individuals with developmental disabilities.
- ADDPC, DDD, and Pilot Parents of Southern Arizona are collaborating to provide Partners in Policymaking. Partners in Policymaking is an innovative leadership training program that teaches people to be community leaders, and to influence systems and policy change at the local, state and national levels. The program is designed for individuals who have a disability and for parents raising children with a disability. Partners provides the most current information and education about disability policy, the legislative process, and local, state and national issues that affect individuals with disabilities. Partners' participants are people who are ready to work for long term systems change and for change in public policy. The overall goal of the program is to foster a partnership between people who need and use services for disabilities, and those who determine public policy. Partners' graduates gain the abilities to teach policymakers a new way of thinking about people with disabilities.
- The Arizona Statewide Independent Living Council (AZSILC) and VR coordinate the Arizona Youth Leadership Forum (YLF). YLF is an innovative, intensive five-day training program for high school sophomores, juniors, and seniors who have disabilities. The program includes structured small and large group activities, field trips, a dance, a formal banquet, and a tour of the state capitol. It provides educational programs on topics such as: positive self-concept, options after high school, the history of disability as a culture, and leadership responsibilities. Staff and presenters who engage with the student delegates include disability community leaders, legislators, and numerous role models who have disabilities. Student delegates are assisted in developing a Personal Leadership Plan which includes specific action items that they complete when they return to their communities. Following completion of YLF, student delegates serve as a youth voice to inform the Arizona State Plan for Independent Living (SPIL), and are assigned a mentor for on-going support for one year.